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Virtuous design for e-health: first sketch of an ethical framework actionable in practice

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ABSTRACT *Mobile health apps are booming but they raise complex ethical issues. Research on ethical issues in e-health is usually focused on the downstream part of the design process. This paper focuses on the upstream part and explores how we can embed values into digital health artifacts at the early stages of the design process, in a virtue ethics perspective specific to e-health. What does a virtuous design for e-health consist of? How to design for e-health virtuously? In order to address these questions, existing ethical frameworks in design are of limited interest. For that reason, we developed a first sketch of an ethical conceptual framework that is specific to the challenges of e-health and that is actionable in practice. It is made of 12 virtues to be considered at the early stages of any e-health design project that claims to be 'good'. This paper aims to introduce the framework and open a discussion on it. First, we present our theoretical approach by defining design ethics and exploring actionable values. Second, we describe two e-health design cases through the lens of these values and we extract from them other values. Third, we introduce the first sketch of our ethical framework in design for e-health as a work-in-progress tool for framing design-led innovation in e-health.*

Keywords: e-health, ethical design, virtuous design, ethical framework, design for e-health.

Introduction

Digital health is a major transformational force today in the health sector (Meskó et al. 2017). Mobile health apps are booming, including mental health (Anthes 2016). However, they tend to be controversial because they raise complex ethical issues, such as privacy, accessibility, or free informed consent (Wadhwa and Wright 2013). Research on ethical issues in e-health is usually focused on the downstream part of the design process, exploring ethical impact assessments or intertwined ethical and legal challenges (George et al. 2013). This paper focuses on the upstream part and explores how we can embed values into digital health artifacts at the early stages of the design process, in a virtue ethics perspective specific to e-health. What does a virtuous design for e-health consist of? How to design for e-health virtuously? In order to address these questions, existing ethical frameworks in design are of limited interest, because they are either very general and not specific to the health sector (Van den Hoven, Vermaas and Van de Poel 2015), or very restricted to targeted issues (Harris 2014). For that reason, we developed a first sketch of an ethical conceptual framework that is specific to the challenges of e-health and that is actionable in practice. It is made of 12 virtues to be considered at the early stages of any e-health design project that claims to be ‘good’. This paper aims to introduce the framework and open a discussion on it.

Theoretical approach

Ethical design

Ethics is commonly defined as a system of values, principles and rules that guide action towards the good. A principle or rule is used to frame the decision that leads to action (e.g. ‘treat others as you would like others to treat you’) by referring to a value (e.g. reciprocity). Applied to design, ethics can be defined as follows: an approach or a process¹ is used to frame the project that leads to an artifact (e.g. biomimicry) by referring to a value (e.g. sustainability). It means that values can be expressed and embedded into artifacts (Van den Hoven, Vermaas, and Van de Poel 2015). Therefore, ethical design requires identifying values to be incorporated into artifacts, and ethical design for e-health requires identifying values that are specifically relevant to be incorporated into e-health artifacts. For instance, as the right to be left alone and to be free of surveillance, privacy is a typical value to be incorporated into a mobile health app. But what does it mean to incorporate values?

Virtuous design

Among the different types of ethics, virtue ethics appears to be the most suitable ethics for any design that seeks to embed values into artifacts at the early stages of the design process. In virtue ethics, a good action depends on a virtuous person. Applied to design, it means that a ‘virtuous designer’ carries out a ‘good design’. For instance, to be incorporated into a mobile health app, the value of privacy can be early integrated into the design process only if it is expressed from the outset by the designer or the design team as an essential requirement *and* materialized in the process through actionable design principles, such as those of Privacy By Design (Cavoukian 2009). In other

¹. We consider here that the equivalent in design of a principle or rule is an approach or a process.

words, virtuous design for e-health can only be achieved if the design process is guided by predefined values that are specifically relevant to an e-health context, consciously claimed as such by the designer/design team, and actionable in practice. However, one is not born but rather becomes a virtuous designer/team, especially in healthcare: it's something to be worked on and built on.

Exploring values

This sub-section is an attempt to explore existing frameworks and to identify in them values that are *specifically relevant* and *actionable in practice* in design for e-health.

Design for Values (DfV)

Design for Values is a broad approach to the ethics of design that is not specific to the health sector (Van den Hoven, Vermaas, and Van de Poel 2015). However, it offers a framework of interest based on 11 values that can help us identify values that are specifically relevant in design for e-health. The 11 values of the DfV approach are the following:

- 1) Accountability and Transparency,
- 2) Democracy and Justice,
- 3) Human Well-Being
- 4) Inclusiveness,
- 5) Presence,
- 6) Privacy,
- 7) Regulation,
- 8) Responsibility,
- 9) Safety,
- 10) Sustainability,
- 11) Trust.

Among them, we will keep the following values in order to embed them in our framework.

Inclusiveness, Privacy, Safety and *Trust* are already well known in existing research on e-health (George et al. 2013), so we consider them as obviously relevant in design for e-health, since they are already admitted as such and related to actionable approaches in practice (e.g. inclusive design, Privacy by Design, engineering design...). *Accountability, Transparency, Democracy, Justice* and *Sustainability* are relevant for any kind of ethical design, including design for e-health, and they are also related to actionable approaches (open design, participatory design, ecodesign...).

However, we will not keep the values of *Human Well-Being* and *Responsibility* because we consider them tautological in a health context. We will not keep the value of *Regulation*, because we consider it related to legal and governance challenges more than ethical ones. We will not keep the value of *Presence*, because we consider it encompassed in Trust.

To be noticed: already known in existing research on e-health, the value of User Autonomy is missing in the DfV approach.

Design for social innovation (DfSi)

Design for social innovation has emerged over the past two decades as a new paradigm for design (Bason 2012; Mulgan 2014; Manzini 2015), that is today more broadly called ‘social design’ and based on the central value of the Common good (Tromp and Hekkert 2018). In that sense, DfSi can be seen as a value-based design approach, intertwined with ethics. Often based on citizens’ local initiatives involving a large range of participants, it is driven by 4 main values: the value of Common Good (designing for collective ends to improve the society at large), the values of *Democracy* and *Justice* (participatory design with stakeholders on equal terms) and the value of *Sustainability*. Only the value of Common good is new here, compared to the DfV approach. However, we will not keep it since we consider it very broad, tautological in a health context, and not specifically relevant in design for e-health.

Responsible innovation in health (RIH)

Responsible innovation in health has been characterized through the integrative RIH framework by Pascale Lehoux and collaborators (Pacifico Silva et al. 2018). It is of interest for us because it is specific to the health sector. It is comprised of 9 dimensions organized within 5 value domains.

Table 1. Overview of the values from the RIH framework

Value domains	Specific values (dimensions)
Population health	Health relevance; Mitigation of Ethical, legal and social issues; Health equity
Health system	Inclusion (of stakeholders); Responsiveness; Level of care (compatibility)
Economic	Frugality (greater value using fewer resources)
Organizational	Alternative business models (that benefit more society)
Environmental	Eco-responsibility

Although the RIH framework is specific to health, several of the values it offers are quite similar to those that we have found in the DfV and the DfSi approaches. *Health equity* is a health version of Justice. *Inclusion* of the health system stakeholders is a variant for *Democracy*. *Frugality* and *Eco-responsibility* are variants for Sustainability. The only new values here are those related to the Organizational and Health system domains. They are highly relevant in design for e-health considering the strong business and public health components of e-health (Eysenbach 2001).

Summary of selected values from literature review

In order to build our framework, we will select the following set of 10 values that we consider both relevant and actionable in design for e-health:

- 1) Accountability,
- 2) Transparency,
- 3) Democracy,
- 4) Justice (i.e. Health equity),
- 5) Inclusiveness,
- 6) Privacy,
- 7) Safety,
- 8) Sustainability,
- 9) Trust,
- 10) Inclusion of Health system.

Cases

Improving the follow-up of chronic insomnia

Som'Health is a project-grounded research focused on chronic insomnia. The aim of the project is to show that a digital service based on an app, and associated with a connected bracelet, can be useful for educating and monitoring insomniacs, if it is integrated into a care network supported by professionals and expert patients. The project revealed that several values were central and essential.

First, Privacy, because of personal sleep data collected through a sleep diary on a daily basis and possibly shared on digital social networks. Second, Democracy and Participation, since the digital diary was co-designed and tested with various stakeholders (patients, sleep specialists, nurses, secretaries, family doctors, psychologists) following a real shared decision making process. Third, Trust and Safety, since patients expressed strong concerns regarding personal data, information systems and databases. All of these values (Privacy, Democracy/Participation, Trust/Safety) are consistent with our literature review.

But there are two more values that appeared as central in the project. First, the value of Attention, in the sense of preserving the user's attention. It's not only about avoiding distraction (Pang 2013) but also supporting the information ecology between the various tools offered through digital and non-digital solutions. Second, the value of Self-Representation, coming from the need for a visual language that could make sense for the patients. This value was identified by the researchers from the analysis of patients and caregivers feedback at each iteration of the design of the sleep agenda, during the co-design workshop. As a subjective complaint, chronic insomnia requires a monitoring tool that allows patients to express their subjective lived experience (Figure 1).



Figure 1: Sleep timeline in Som'App

Improving access to psychotherapy

Psydia is a project-grounded research focused on psychotherapy. The aim of the project is to explore what design can do for psychotherapy in a digital age beyond the tendency to strengthen the false divide between the ‘online’ and the ‘offline’ (through preconceived ideas such as online therapy services). Conducted from Fall 2016 to Fall 2018 with five student cohorts who designed 69 prototypes of a mobile app, the project enabled a large range of ideas to be generated.

Considering the results, students did not give a great deal of attention to key values such as Privacy, widely neglected. Inclusiveness or Sustainability were even completely avoided. They focused more on Trust. For instance, the ‘Explorapie’ project aims to increase Trust in therapists that we browse online considering the lack of public awareness in therapies and the difficulty to rely on a therapist profile on a screen: it offers to match a patient with the right therapist after accessing relevant information about the therapy types, such as videos, testimonials... (Figure 2).



Figure 2: Screenshots of the project ‘Explorapie’

As the students approached the project mainly with a patient focus, we also conducted codesign sessions with clinicians (psychologists). An unexpected value appeared during conversations with clinicians. It was phrased like this: '*It's up to you to decide if you need to see a therapist*'.

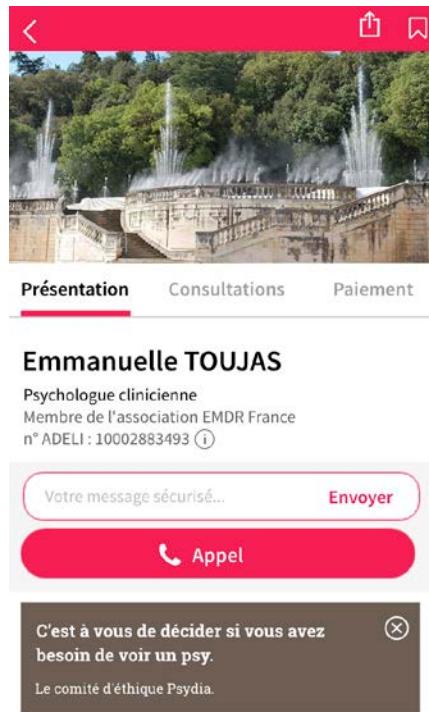


Figure 3: Codesigned therapist's profile (top of page)

We decided to embed it as it is into the interface, and to display it as a recommendation for patients coming from a sort of built-in ethical committee (Figure 3). The value that lies behind is Self-Determination. Clinicians always try to support patients' self-determination, which is widely recognized by the Ethics Codes of many psychological associations.

The virtuous design for e-health framework

General description

Inspired by previous work from both of us (Catoir-Brisson 2019; Vial 2019), this virtuous design for e-health framework is an attempt to frame design-led innovation in e-health through ethical concepts that are actionable in practice. The framework consists of 12 values and 12 series of related approaches (examples of appropriate methods/processes).

Values and approaches are distributed on both sides of a central axis and should be read from the bottom up along the axis in a three-level progression: individual, relational and systemic (Figure 4). Each level includes the values that must be incorporated into the e-health artifact from a particular design perspective.

The individual level corresponds to the perspective of the individual's relationship to himself or herself: it includes the values of the Self, Attention, Privacy, and Safety. The relational level corresponds to the perspective of the individual's relationship to other people, to groups to which

he or she belongs, or to norms that act on the artifact: it includes Trust, Transparency, Accountability, and Inclusiveness. The systemic level corresponds to the perspective of the individual's belonging to organizations, institutions, society as a whole and the planet itself: it includes Inclusion of Health system, Profit in second place, Justice, and Sustainability.

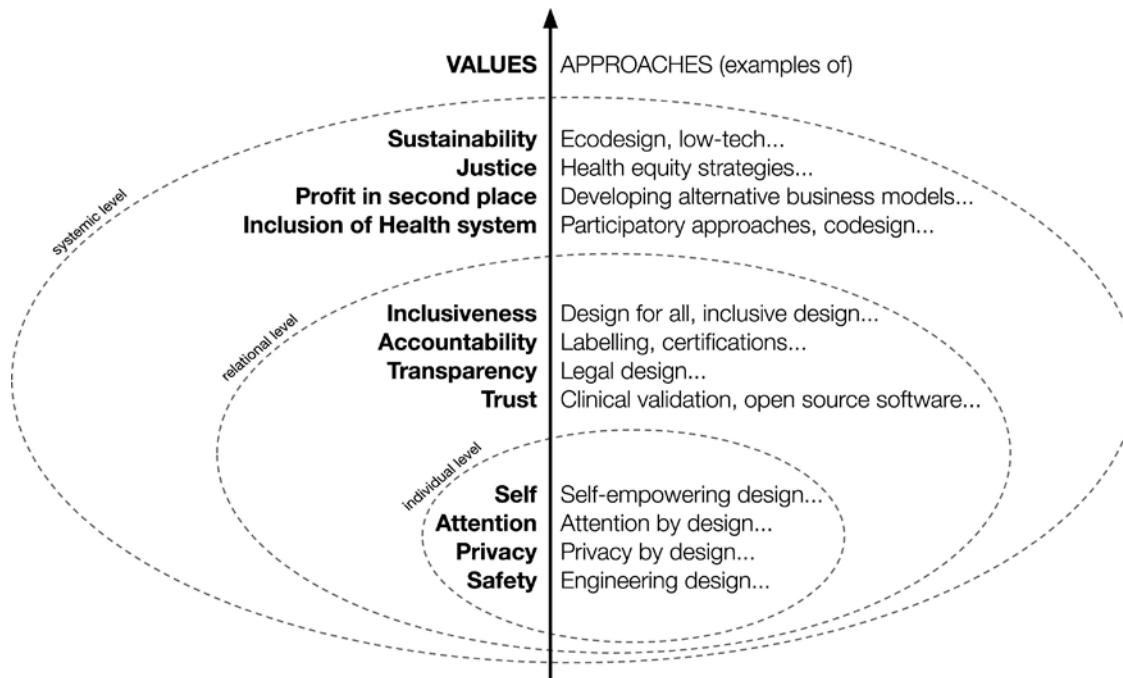


Figure 4: The virtuous design for e-health framework

Values

The values offered in the framework consist of a final set of 12 values: 10 values from our brief literature review and 2 additional values (marked below with an asterisk *) from our short cases studies. Although these 12 values are different, there may be some overlap between them.

Individual level

Safety is the value of doing no harm, physical (e.g. used materials) or mental (e.g. brain effects).

Privacy is the value of preserving confidential any personal data.

Attention * is the value of respecting the ability of users to freely apply their minds to something.

Self * is the value of respecting and supporting the patient's autonomy or self-reliance, it encompasses both Self-Representation (2.1) and Self-Determination (2.2).

Relational level

Trust is the value of reliance on the credibility, efficacy and morality of the service.

Transparency is the value of open communication to users, with no lies or dark patterns.

Accountability is the value of providing evidence of ethical commitment.

Inclusiveness is the value of including human diversity and various contextual situations of users.

Systemic level

Inclusion of Health system is the value of involving health stakeholders and considering health institutions.

Profit in second place is the value of developing business models that benefit society as a whole.

Justice is the value of including vulnerable groups and promoting equity in health.

Sustainability is the value of reducing the negative environmental impacts of health activities.

Approaches

The approaches listed in the framework are examples of possible relevant design methods and processes for incorporating related values into projects/artifacts. Most of them are well-known and do not need any definition. A few of them are our own definition and would need further inquiry, such as Health equity strategies or Self-empowering design.

It is important for us to highlight that the main contribution of this paper lies in values.

By mentioning possible design approaches, we want to underline the fact that those values are actionable. Of course, we assume that many other possible approaches must exist or are missing here. We would be interested in improving the approaches side of the framework in future work.

On the same note, this framework does not pretend to be comprehensive, it is a first sketch, a basis for opening discussion on these complex issues.

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